

## Incidence, prevalence and challenges of managing CTEV in the Top End

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### Abstract

We conducted a retrospective review of prospectively collected data on all patients treated for idiopathic Congenital Talipes Equinovarus (CTEV), or clubfoot from 2000 to 2011. There was a total 114 cases of CTEV across the Top End (northern health district within Northern Territory, NT), with 84 (74%) identified as indigenous. The overall incidence of CTEV in the Top End was 3.2:1000 births. In the Top End indigenous population the incidence was 5.7:1000 births compared to non-indigenous at 1.2:1000. So, a Top End indigenous child is almost five times more likely to be born with clubfoot.

Similar to previous published data, the male to female ratio was 2:1 in both groups. 66% of all Top End children born with CTEV lived in remote locations, 20% from the local Darwin area and 13% from local Katherine area. The 76 patients living in remote regions of the Top End represented 37 individual remote communities. From the information available, 27% of cases were left unilateral, 25% were right unilateral and 48% cases were bilateral.

After adopting the international gold standard treatment for CTEV, the Ponseti method, we anticipated improved overall outcomes for treatment of CTEV. We have however observed clinically that the goals of Ponseti treatment are not always being achieved, resulting in perceived higher rates of recurrence than expected for the Ponseti protocol. The limitations of early data collection restrict us from making more definitive conclusions.

As with managing other chronic conditions, the remote and widespread location of many indigenous families affected by CTEV in the Top End remains a challenge. There is also the stigma of wearing orthotics, an absolute necessity to maintain foot corrections over subsequent years.

Further detailed study is needed to explore the shortfalls, quantify the success of the Ponseti method and evaluate rates of surgery, complications, attendance and compliance, as well identify barriers to cost effective evidence based provision of Ponseti care to CTEV patients in the Top End of NT.

We believe the key to improved CTEV treatment is improved health literacy. We propose the implementation of relatively low cost additions such as a CTEV coordinator with indigenous cultural expertise and better provision of information, as well as upskilling of remote health workers in elements of the Ponseti method. This could improve education, compliance, attendance and ultimately the outcomes for individuals and families

### Introduction

Congenital Talipes Equinovarus (CTEV), or clubfoot is a deformity recognizable at birth as a plantar flexed, inverted foot with the forefoot adducted. It is differentiated from positional talipes or metatarsus adductus by simple methodical examination.<sup>1</sup>

Internationally, the incidence of CTEV ranges from 0.9 – 6.8:1000 births<sup>2</sup>, but in Australia, a national rate has never been estimated. The rate in Western Australia (WA) was reported as 1.25: 1000 (3.49 in the indigenous population)<sup>3</sup> and in South Australia (SA) it was reported as 1.1:1000 with an increased risk identified if of Aboriginal maternal descent, but not presented as a separate incidence rate.<sup>4</sup>

Previously, acute surgical correction at the appropriate age was the recommended treatment. In the 1950s, Ignatio V Ponseti began using manipulation, serial casting and bracing to manage clubfoot gradually and from infancy. Helped by long term studies of outcomes, Ponseti's method of CTEV treatment is now widely considered both curative and cost-effective, compared with acute surgical corrections alone.<sup>6-13</sup> In fact, the majority of infants treated with the Ponseti method require no surgery beyond percutaneous tendo-achilles tenotomy, a procedure that can be done in an outpatient clinic.<sup>7-13</sup>

The Ponseti method has a success rate of up to 92-100% worldwide, with surgical rates decreasing by 7% per year after peaking in 2000-2001, and only 10% of cases requiring surgical intervention beyond a tenotomy to achieve good functional outcome.<sup>14</sup>

In the Top End, our practice has gradually shifted in line with the increasing evidence over the last 15 years from operative surgical management to the less invasive Ponseti protocol, although surgery is still regularly considered. Our service provision is influenced strongly by the timing, availability and guidance of quarterly visiting Paediatric Orthopaedic surgeon from interstate, having no local paediatric orthopaedic specialist in the NT.

It is known from the limited Australian epidemiology studies on CTEV that there is an increased prevalence of the deformity in indigenous Australians<sup>3,4</sup> as with other indigenous groups internationally.<sup>15,16</sup> We set out to quantify the high incidence in the Top End geographical area, which provides services for CTEV through the orthopaedic and physiotherapy departments of Royal Darwin Hospital, in conjunction with colleagues at Katherine Hospital and limited support in remote communities.

We intended to gather data to evaluate our clinical impression that outcomes and surgical rates have improved over the past 15 years as the service transitioned to following the Ponseti method, but data was insufficiently available, or of insufficient quality to do so. It was also hoped to quantify the perceived poor compliance with attendance and bracing, but again it was not possible to clearly determine this from the data available.

This has led us to reflect extensively on the best management model for our CTEV patients, particularly given the unique cultural and geographical barriers to receiving Ponseti treatment in the Top End. We also consider how we might best utilize existing resources and attract additional resources to manage CTEV in an evidence based culturally sensitive manner, including future research opportunities.

## Methods

This review was guided by the availability of a database compiled and maintained by physiotherapists working with CTEV patients at RDH since 2000. We retrospectively reviewed this prospectively collected clinical information.

The database includes all infants treated for CTEV at RDH and KDH throughout the last 15 years. It included all cases referred to physiotherapy services at any age, including those relocating to the Top End prior to completion of their clubfoot treatment. We included only patients born 2000-2011 to allow a sufficient follow up period to be observed, in line with best Ponseti practice.

Patients were excluded if they had positional talipes, metatarsus adductus, equinovalgus, or syndromic CTEV (associated with other conditions); terminations and stillbirths.

Using birth and population data from ABS<sup>17,18</sup> the incidence for Clubfoot in the Top End region of the NT was calculated. ABS data allowed the number of total and indigenous births in NT to be specifically identified by region from 2004-2009 inclusive. This allowed calculation of birth data specific to the Top End. Data available for the other years did not include specific location, providing indigenous and non-indigenous birth data for the NT but not specifically the Top End region. The rate was consistent through the years 2004-2009, hence an average Top End birth rate was extrapolated and applied to the ABS data for the years 2000-3 and 2010-11.

**Table 1 International Incidence of CTEV**

Country	Incidence /1000 live births	Data Source
Australia: Aboriginal	3.49	Carey M, Bower C, Mylvaganam A, Rouse I (2003) Talipes equinovarus in Western Australia. <i>Paediatric Perinatal Epidemiology</i> 17 (2): 187-194
Australia: Caucasian	1.11	Carey M, Bower C, Mylvaganam A, Rouse I (2003) Talipes equinovarus in Western Australia. <i>Paediatric Perinatal Epidemiology</i> 17 (2): 187-194
Belgium	1.6	Paton R, Fox A, Foster A, Fehily M (2010) Incidence and aetiology of talipes equinovarus with recent population changes. <i>Acta Orthopaedica Belgica</i> 76 (1): 86-89
Denmark	1.2	Krogsgaard M, Jensen P, Husted H, Lorentzen J, Hvass-Christensen B, Christensen S, Larsen K, Sonne-Holm S (2006) Increasing incidence of club foot with higher population density: incidence and geographical variation in Denmark over a 16 year period. <i>Acta Orthopaedica</i> 77 (6): 839-846
Hawaii	6.8	Dietz F (2002) The genetics of idiopathic clubfoot. <i>Clinical Orthopaedics and Related Research</i> 401: 39-48*
India	0.9	Mittal R, Sekhon A, Singh G, Thakral H () The presence of congenital orthopaedic anomalies in a rural community. <i>International Orthopaedics</i> 17 (1): 11-12
Japan	0.87	Yamamoto H (1979) A clinical, genetic and epidemiologic study of congenital club foot. <i>Journal of Human Genetics</i> 24 (1): 37-44
Malawi	2	Mkandawire N, Kaunda E (2004) Incidence and patterns of congenital talipes equinovarus (clubfoot) deformity at Queen Elizabeth Central Hospital, Banter, Malawi. <i>East and Central African Journal of Surgery</i> 9 (2): 28-31
Papua New Guinea	2.7	Culverwell A, Tapping C (2009) Congenital Talipes Equinovarus in Papua New Guinea: a difficult yet potentially manageable situation. <i>International Orthopaedics (SICOT)</i> 33: 521-526
Philippines	0.76	Aguilar J (nd) Ponseti method for treating clubfoot in older children and children with previous unsuccessful subtalar releases: short term results. Accessed online at: <a href="http://www.ponseti.info/v1/index.php?option=com_content&amp;task=view&amp;id=66&amp;Itemid=63">www.ponseti.info/v1/index.php?option=com_content&amp;task=view&amp;id=66&amp;Itemid=63</a> on 18/08/2010
Sweden	1.4	Wallander H, Hovelius L, Michaelsson K (2006) Incidence of congenital clubfoot in Sweden. <i>Acta Orthopaedica</i> 77(6): 847-852
Uganda	1.2	Pirani S, Maddumba E, Mathias R, Konde-Lule J, Penny N, Beyeza T, Mbonye B, Amoni J, Franceschi F (2009) Towards effective Ponseti clubfoot care: the Uganda Sustainable Clubfoot Care Project. <i>Clinical Orthopaedics and Related Research</i> 467: 1154-1163
USA	1	Dietz F (2002) The genetics of idiopathic clubfoot. <i>Clinical Orthopaedics and Related Research</i> 401: 39-48*

Source: Global Clubfoot Incentive<sup>2</sup>. [Globalclubfoot.org/clubfoot](http://Globalclubfoot.org/clubfoot)

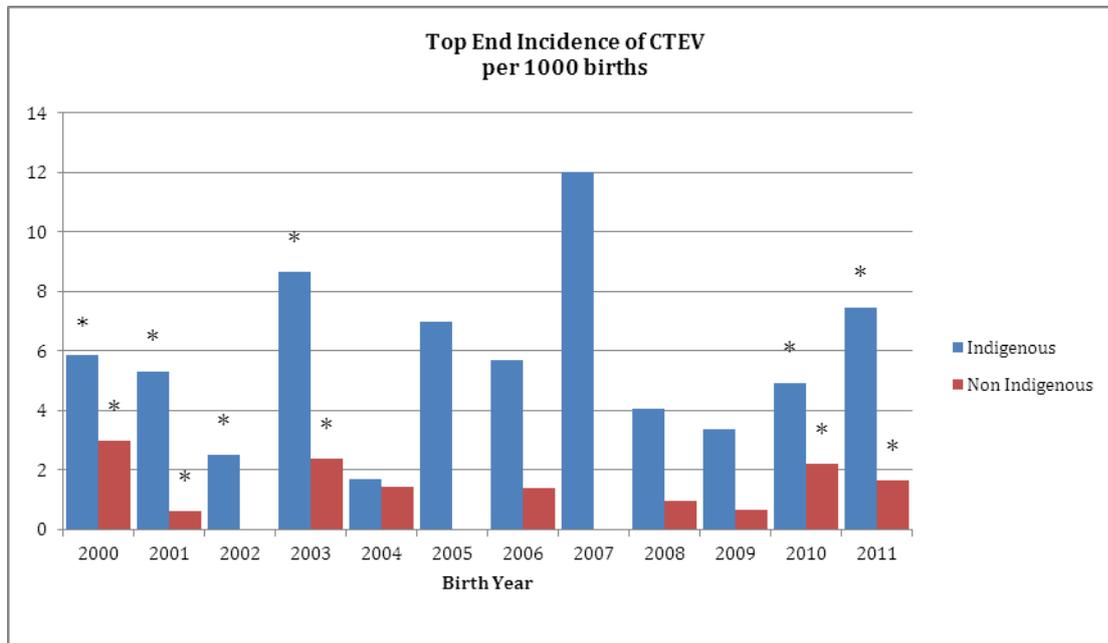
## Results

114 cases of CTEV were identified from 2000-2011. 74% were of indigenous background, and 66% lived in remote locations.

Incidence for CTEV in the Top End was calculated from the entire dataset (2000-2011 birth cohorts). Incidence for CTEV in the Top End was 3.2:1000 births. For indigenous births, the incidence is 5.7:1000 births, and non indigenous incidence 1.2:1000.

Figure 1 graphically highlights the increased incidence (per 1000 births) in the indigenous population compared to the non indigenous population over the period under review.

Figure 1 Incidence of CTEV in Indigenous and Non-Indigenous births, Top End NT



\* indicates rate based on Top End birth data extrapolation

Table 2 shows a summary of CTEV for each birth year, including ethnicity, location, gender and laterality.

Similar to previous published data, genders were represented as 68% of indigenous patients being male, 31% indigenous cases were female, 67% of non-indigenous were male and 33% non-indigenous were female.

A total of 76 individuals lived in remote locations, with 37 separate remote communities identified as their usual place of residence.

Laterality showed an almost identical pattern between indigenous and non indigenous cases, with a male:female ratio of 2:1.

Table 2 Demographics of CTEV in Top End NT 2000-2011

Birth year	Total cases n=114	Indigenous cases	Darwin urban	Katherine urban	Top End remote	Male (Indigenous)	Female (Indigenous)	Left unilateral n=81	Right unilateral n=81	Bilateral n=81
2000	11	7	0	4	7	7 (5)	4 (2)	0	0	2
2001	8	7	2	2	4	4 (4)	4(3)	2	2	1
2002	3	3	0	0	3	2 (2)	1(1)	0	0	1
2003	15	11	2	2	11	8 (7)	7(4)	2	1	1
2004	6	2	2	2	2	4 (1)	2(1)	0	1	2
2005	8	8	0	0	8	6 (6)	2(2)	1	1	5
2006	11	7	5	0	6	7(4)	4(3)	3	3	3
2007	15	15	1	3	11	13(13)	2(2)	4	6	5
2008	8	5	2	1	5	7(5)	1(0)	3	0	4
2009	6	4	1	0	5	3(1)	3(3)	3	2	1
2010	10	6	5	0	5	6(4)	4(2)	2	0	8
2011	13	9	3	1	9	9(6)	4(3)	2	4	6
Total	114	84	23	15	76	76(57)	38(26)	22	20	39
%	100	73	20	13	66	66(68)	33(31)	27	25	48

## Discussion

Very little information is available on the epidemiology and treatment of clubfoot in Australia. We found a higher overall incidence of clubfoot in the Top End compared to WA and SA<sup>3,4</sup>, but most notable was the very high incidence in the indigenous population, approx. 5 times that of the non indigenous population. Furthermore, compared to other States and Territories, indigenous people make up a much greater proportion of the population of the NT – 41% - intensifying our resolve to improve the analysis and treatment of CTEV in the Top End.<sup>18</sup>

The Ponseti method is accepted as the gold standard for treatment of CTEV. It is minimally invasive and can largely be implemented by any health worker with the appropriate training.<sup>6</sup> Compared to acute surgical correction alone, it has been shown to be more effective in terms of cost and overall results.<sup>5,13</sup>

Typically, plaster casting commences in the first few weeks of life, weekly for six weeks. Progress is continually evaluated, with casting tailored appropriately, and in accordance with Ponseti guidelines. In 85% of cases a percutaneous tenotomy is indicated, which is followed by another 2-3 weeks in plaster. The correction must then be maintained with bracing through the early years of rapid growth and development (recommended to 4 years of age).<sup>6</sup>

Supporting a remote indigenous parent with their infant to stay in Darwin or Katherine for serial casting requires a measured, coordinated approach from multiple health professionals. The pressure on a remote family to return to the community is heightened when there is a lack of local support. However we believe initial compliance is facilitated by the fact that the parents can see the clubfoot deformity at birth.

More of a challenge is convincing families of the importance a minor surgical procedure when the foot deformity appears 'resolved.' Even more so is the challenge of maintenance therapy. We have difficulty convincing families and carers that the clubfoot will recur without diligent use of night-time boots and bar. Similarly bilateral abduction braces, known as "boots and bars", may be less likely to be worn regularly in an environment where children have predominantly bare feet, and where Mothers and children may be "shamed" culturally for noticeable differences from their peers.

We believe that there is a role for visual aids such as colour pamphlets with a clear explanation of the condition and culturally appropriate pictures indicating what happens with and without treatment.

Short explanatory videos in the correct language and with culturally appropriate examples may be of use if shown in the community and highlight the community's important supportive role.

Non-compliance with boots and bars is a major challenge recognised by Ponseti professionals around the world. An excellent correction achieved over six weeks can be undone in very short periods. A novel idea is to create a 'healing bar' for mounting the boots, in lieu of the typical stark metal bar. This could be a stick recognised as being from the community and which has undergone a ceremony or blessing, likely by a tribal elder. It could have traditional painting and markings by a community artist. Community involvement, from multiple communities, would be sought before trialling such a proposal, but we believe it has merit.

Most importantly, we believe that there is a role for increased culturally engaging community support, such as a coordinator with appropriate cultural training. Being involved with the health team's Ponseti treatment from early days and following up with regular contact in person, via video conferencing and via telephone to keep families engaged in treatment is worthy of strong consideration. As well as aiming to improve compliance rate, we would also anticipate a significant improvement in attendance at clinic, and earlier identification of relapse or other concerns. A similar program on a larger scale has been implemented across the NT to address the high truancy rate in indigenous communities.

Finally, given our high incidence and difficulty drawing conclusions about the success of our current methods, we intend to seek resourcing to improve data collection and comprehensive evaluation of our program.

Through best utilisation of existing resources, targeted investment in culturally appropriate additional support and critical evaluation of services we hope to, provide evidence based culturally sensitive care to the many families in the Top End affected by CTEV.

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## Presenters

**Kelly Paterson** is a physiotherapist working in paediatrics at Royal Darwin Hospital, providing physiotherapy services to inpatients and outpatients from all medical and surgical areas including neonates, infants and children. Kelly has been working in Darwin for over 18 months, and has previously worked in paediatric physiotherapy in Brisbane and south-east Queensland, with an emphasis on Paediatric orthopaedic work. With the support of the RDH orthopaedic team, Kelly coordinates and provides Ponseti casting management for infants and children with clubfoot from remote as well as metropolitan areas of the Top End. Kelly is hoping to be travelling to Iowa (USA) later this year for specialised training in the Ponseti method.

**David Horman** is an orthopaedic registrar at Royal Darwin Hospital. In his last year as a medical student at Flinders he spent time in South Africa and on Groote Eylandt in East Arnhem Land. He did his intern years at Ballarat and in 1997 won awards from the AMA and the Diners/AMSA Rural Scholarship for promoting medicine in rural and remote Australia.